WHY FATIGUE PLAGUES SO MANY WITH SPONDYLOARTHRITIS

BOOSTING YOUR MENTAL HEALTH AND WELLNESS AMID COVID-19

YOUR STORIES: AVOIDING THE ER ROLLERCOASTER
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SAA MISSION
To be a leader in the quest to cure ankylosing spondylitis and related diseases, and to empower those affected to live life to the fullest.

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HOW CAN WE HELP?
SAA’s staff and board of directors are sending our wishes for health and safety to you and your loved ones. Is there anything we can do to help? What are your needs? Reach out to us at info@spondylitis.org. Now, and always, you’re on our minds and we are here for you.

Annual subscriptions are free with SAA membership. Content is for informational purposes only. SAA does not endorse or recommend any medications or products for spondyloarthritis, and always advises that you seek the counsel of a physician before initiating any treatment for spondyloarthritis.

SAA SPOTLIGHT:
As COVID-19 continues to spread around the world, the future has never felt so unpredictable. Perhaps this is especially true for those living with chronic conditions that require daily health precautions, access to critical medications, and a feeling of connectivity to others who understand the special needs you grapple with every day.

Right now, we’re doing everything possible to sustain daily operations and continue to provide support to those we serve. While there’s a lot of uncertainty, we know that we need to adapt fast to our changing reality. Now, more than ever, our community needs us. And, as always, we need you.

SAA has compiled a comprehensive trove of information on the various ways COVID-19 impacts the spondyloarthritis community. Written with the guidance of leading experts in the field, this resource is updated continually and always reflects the most up-to-date knowledge and information available. Bookmark spondylitis.org/coronavirus and check back often for updates.

We have also, in partnership with members of our Medical and Scientific Advisory Board, spearheaded research into the possible impact spondyloarthritis, and medications used for spondyloarthritis, may have on COVID-19.

Understanding the effects of spondyloarthritis, and the medications used in treating it, on COVID-19 is crucial for patients, doctors, and researchers alike. I would like to thank all those who have already participated and will continue to respond to follow-up surveys every four weeks, for an estimated six months.

If you haven’t yet taken part, I urge you to consider doing so. You do not have to have contracted COVID-19 to participate. We also invite those who live in your household to enroll in the control group to help us deliver clearer answers to you. This critical research will help answer urgent questions for the benefit of everyone in the spondyloarthritis community. You will find this survey at spondylitis.org/coronavirus.

In times like this, we’re reminded of how interconnected we all are. Please know that we are here because of you and we are here for you. Without you, none of this is possible.

Stay safe and well, and please reach out to me at Cassie@spondylitis.org and let me know how you are doing and how we can help. SAA’s staff may be working from 12 different locations right now, but we remain united in our goal of serving our constituents.

All my best,
Cassie

Cassie Shafer
Chief Executive Officer
LETTERS TO THE EDITOR:

“I wanted to share this tattoo that I have. I’ve been a long time member of the SAA, and have been taking Enbrel for 15-plus years now. I’ve told people the Spoon Theory more times than I can count. I’ve had AS since 1982 and was also diagnosed with PsA 10 years ago. Below the Enbrel/spoon/SAA logo is a spartan helmet with the Greek words “Molon labe.” This is what Leonidas is reported to have said to Xerxes when told to lay down his arms and surrender. He was saying if you want it, come take it. This is my view on my disease. I have AS/PsA. They don’t have me. I fight everyday with the effects of AS, and at close to 59 years old, I have no intention of stopping.

Fifteen years ago, I was close to not being able to walk. I couldn’t move my head and breathing was an agonizing chore. Sleep came in 1-3 hour periods. I was miserable. Finding treatments that worked for me gave me a new lease on life.

The SAA over the years has allowed me to educate myself (and others). Your continued mission to provide everyone, including the medical field, with information has been invaluable to Spondys.”

~Ken Delano

“Thank-you, thank-you. The [electronic] newsletter addressing coronavirus and spondylitis was extremely informative and much appreciated. As a long time AS patient (diagnosed in 1985) who recently started on a biologic (May, 2019), your newsletter provided me with much needed information. (Editor’s Note: Please see spondylitis.org/coronavirus for regularly updated coronavirus resources and information.)

Keep up the good work. The newsletter provides extremely valuable information. (I have provided copies of several past articles to my rheumatologist.)”

~Paul Sembrat

“THANK YOU for sharing this latest information on COVID-19 and spondylarthritis with us. The explanations were clear (and truthfully, reassuring). It was interesting to read the line re: those who are HLA-B27 positive demonstrating natural immunity toward some viral infections.

Again, thank you for your ongoing dedication to the support of people with spondylarthritis.”

~Jeanette Szretter
WHY FATIGUE PLAGUES SO MANY WITH SPONDYLOARTHRITIS:
A CONVERSATION WITH LEADING RESEARCHER, AND SPONDYLOARTHRITIS WARRIOR, DR. MECHIEL KORTE

The connection between fatigue and spondyloarthritis, as well as other inflammatory arthritic conditions, is well known and documented, but not always well understood. Dr. Mechiel Korte has extensive expertise in this, both as an esteemed researcher dedicated to studying fatigue, as well as someone living with spondyloarthritis for 44 years. He recently published an in-depth article on fatigue in inflammatory rheumatic conditions in the peer reviewed journal, Rheumatology, and we were thrilled to have the opportunity to discuss the topic with him. As timing would work out, the COVID-19 pandemic was underway, and we were able to touch on this pressing topic in our interview. Our deep gratitude to Dr. Korte for discussing both fatigue, and his thoughts on COVID-19 with us.

You often call people with spondyloarthritis “warriors.” Can you discuss why?

Many people with spondyloarthritis (SpA) have a gene called HLA-B27. In some people, this gene – in combination with an infection or some musculoskeletal strain or injury (also called mechanical stress) – can trigger SpA. The exact mechanism, however, is still unknown. Why do many of us have this gene when it negatively affects the body? The answer is simple: It does not only produce negative effects. The owners of this gene have a very strong immune defense system, protecting them (fully or partly) from many viruses, such as HIV (AIDS), hepatitis C, influenza, Epstein-Barr virus, herpes simplex virus, and hantavirus infection, and probably even smallpox in the past. That’s why I call people with the HLA-B27 gene – and everyone living with SpA – “warriors.” They are very strong, and genetically speaking, sometimes too strong. The immune response of people with the HLA-B27 gene can be very aggressive, combating viruses, but at the same time this aggressive immune response can have very harmful effects, as we all know too well.

How did you become interested in investigating SpA and fatigue?

When I was a teenager and visited the rheumatologist, in the waiting room I would sometimes see people in wheelchairs, people with bent spines (like my own uncle), or those walking with mobility devices. Since the introduction of biologic drugs, much has improved. Nowadays, SpA often presents like an iceberg. Above water, you don’t see much. But underwater, there are disabling symptoms, including severe fatigue. It is difficult to
How and why does fatigue occur in spondyloarthritis (SpA)?

First, the causes of fatigue:

- **Systemic inflammation**: During the inflammatory process, many immune cells (mitochondria) that produce energy in cells, including brain cells. Consequently, you withdraw socially so that (A) you do not infect others, (B) you do not infect yourself, (C) you do not spread the disease.

Second, the processes that produce fatigue:

- **Inflammation lowers serotonin levels in the brain, a signal is sent to the brain to produce fatigue. People with SpA are not crazy or lazy, they have low serotonin levels.**

Evidence is accumulating that different brain areas are involved in the production of fatigue. For instance, decreased concentrations of these substances affect brain functioning via different routes. As cytokines, such as IL-1, IL-6 and TNF-alpha, contribute to inflammation during the inflammatory process.

Let's discuss treatments – medications and other options for fatigue in people with SpA. In a way, fatigue has many similarities with how you feel after a flu or food poisoning, with one big difference. Inflammation in SpA is often systemic. NSAIDs and biologics can effectively reduce inflammation. If you recover from an infection. But inflammation in SpA is often systemic. NSAIDs and biologics can effectively reduce inflammation. When there is more inflammation in SpA and consequently lower dopamine rates and energizes you toward a distinct goal. Thus, when there is less energy, one is no longer motivated to do things and be socially active, meanwhile spreading the disease. (mitochondria) that produce energy in cells, including brain cells. Consequently, you withdraw socially so that (A) you do not infect others, (B) you do not infect yourself, (C) you do not spread the disease.

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First, trust the medical experts, follow their advice, and ask for help if you need it. The dream that there will come a time when we do my utmost to improve the quality of life of people with SpA is more in inflammation. This is the character flaw! It is a serious symptom of the disease, brought on by systemic inflammation throughout the body (including joints, organs, and other organs). Systemic inflammation can cause a variety of problems, followed by pain, and lack of understanding from others, especially when out in public, because this is the way material. This means that the virus can only spread with the help of other people, including those feeling good and healthy, should respect the 6 feet of distance rule in my opinion. This is crucial!

Normally, with a viral infection, you experience the typical symptoms of fatigue. Fatigue can be a sign of an infection or illness, but it can also be a symptom of other health conditions. Fatigue can be caused by a variety of factors, including lack of sleep, inadequate nutrition, or chronic stress. As someone living with spondyloarthritis and who understands the challenge of fatigue, I decided to focus my research on this specific topic and to do my utmost to improve the quality of life of people with SpA. The severe fatigue is more in inflammation. This work was supported by the Dutch Arthritis Society. For instance, decreased concentrations of these substances affect brain functioning via different routes. As cytokines, such as IL-1, IL-6 and TNF-alpha, contribute to inflammation during the inflammatory process.

I know exactly how it feels. When I realized I was not the only one, I decided to focus my research on this specific topic and to do my utmost to improve the quality of life of people with SpA. The severe fatigue is more in inflammation. This work was supported by the Dutch Arthritis Society. For instance, decreased concentrations of these substances affect brain functioning via different routes. As cytokines, such as IL-1, IL-6 and TNF-alpha, contribute to inflammation during the inflammatory process.

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more research!

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evidence is accumulating that different brain areas are involved fatigue (I have difficulties performing physical tasks); and finally, are at least three different forms of fatigue that can exist in SpA: animal model with the human HLA-B27 gene. Surprisingly, there Medical Center, Dallas, was so kind as to provide us with an gy, Dr. Joel Taurog from the University of Texas Southwestern Yes, there are. This is what I learned from both patients and different parts of the brain?

collaborate much more with people with SpA, because there is so can treat fatigue in everyone with SpA keeps me going. I cannot normally do, therefore causing the person to abstain from behavioral actions have higher energy costs than they in the brain is involved in the regulation of many behaviors, like going to a movie or restaurant. Dopamine produces a motivational signal in the brain. It invigorates and energizes you toward a distinct goal. Thus, when there is more inflammation in SpA and consequently lower dopamine levels in the brain, one is not energized to do things that normally produce pleasure, like going to a movie or restaurant.

Serotonin in the brain is involved in the regulation of many behaviors, because it plays a crucial role in reward-cost valuation. As inflammation lowers serotonin levels in the brain, a signal is sent that behavioral actions have higher energy costs than they normally do, therefore causing the person to abstain from activities to conserve energy. Recently, it became clear that serotonin can directly influence neuronal powerplants (mitochondria) that produce energy in cells, including brain cells. Again, lower serotonin levels give a signal that there is less energy available, which might suppress normal social behavior.

Third, why is fatigue so prevalent: Without a doubt, this is the most difficult question. Normally, illness, including fever and fatigue brought on by infection with a virus or bacteria, can be functional (that is to say, they have an evolutionary or biological benefit). The lower serotonin and dopamine levels produce a feeling of fatigue, and because less energy is available, one is no longer energized or motivated to do things.

Consequently, you withdraw socially so that A) you do not infect other group members, and B) you save your energy to fight the infection and to recover. This is functional and subsides when you recover from an infection. But inflammation in SpA is often a chronic process, so consequently, we often suffer from chronic fatigue. Remarkably, people with SpA who suffer from fatigue seem to have a biological advantage right now because they do not have the energy to be socially active and so they tend to be less exposed as a result. (On a side note, one of the problems in this pandemic is that COVID-19 does not always produce these typical sickness symptoms, such as fever or fatigue, in everyone, so infected people are sometimes still energized and motivated to do things and be socially active, meanwhile spreading the disease.)

Speaking of COVID-19, with the pandemic encircling the globe everything seems to be different. Are you concerned for your safety? What would you like to share about this health crisis with our readers?

There is always a question in the back of my mind of, “What if?” I am not a medical doctor but a neuroscientist who investigates...
immune-brain interactions, including the role of stress. Uncertainty and unpredictability are known to produce stress. Long-term stress is bad for the immune system. So, it is important to control stress levels. The best way to prevent stress is to focus on what you can do. What can we do? Honestly, together we can do so many things.

First, trust the medical experts, follow their advice, and ask questions when you need answers.

Second, the virus does not have legs or wings; it is just dead material. This means that the virus can only spread with the help of people. Thus, stop helping the virus by taking these steps:

A) Wash your hands frequently, for at least 20 seconds.
B) Regularly clean and disinfect doorknobs, faucets, and other things you touch often.
C) Do not touch your nose or mouth with your hands or fingers, especially when out in public, because this is the way COVID-19 is most effectively spread.
D) Maintain physical distance from other people, remaining at least 6 feet apart (no hugs, no handshakes).
E) Avoid group gatherings, even if it means staying away from celebrations, birthday parties, and the like.
F) If a family member does not feel well (coughing, sneezing, fever), it is ideal for all to stay at home for 14 days.

Third, giving support to others is one of the best ways to suppress your own, and others’ stress levels. Even when we cannot physically visit relatives and friends (especially if we, or our loved ones, are at higher risk), we can maintain our connections virtually, and offer support through phone calls, emails, and online platforms.

If you are able and if it is safe for you to do so, offering to pick up medications and groceries (or helping order them online) can go a long way for those most at risk. If you are at higher risk, asking loved ones to help with these needs may provide them with a welcome opportunity to support you, and lower their stress levels by being supportive in this way. Please keep in mind that you should still maintain the 6-foot distance when delivering or receiving supplies.

**What worries you most?**

At this moment, it is clear that the virus produces asymptomatic behavior in some. What does this mean to us all? In Iceland, they tested a very large group of the population and the findings indicated that COVID-19 can produce a wide spectrum of symptoms, from people who have no symptoms at all (including many children), to people with cold-like symptoms (runny nose, congestion, sore throat, no smell, no taste), to people with high fevers, muscle aches, shortness of breath, cough, and fatigue.

Normally, with a viral infection, you experience the typical symptoms mentioned above, including fatigue. With COVID-19, however, some people get infected with the novel coronavirus without knowing it, and they may spread the disease unwittingly. This is probably one of the reasons why COVID-19 is so effectively spreading around the world. Therefore, all people, including those feeling good and healthy, should respect the 6 feet of distance rule in my opinion. This is crucial!

**Thank you very much for that! Getting back to our original topic: Is fatigue caused or made worse by something a person does or doesn’t do?**

First of all, let me make something clear: The severe fatigue associated with spondyloarthitis is a consequence of the inflammatory disease; it is not a character flaw. A strong character can probably make it even worse. For many years, I just ignored the feelings of fatigue and finally I ended up with serious burn-out. One must listen to their body’s signals. Often, I was frustrated – which in itself uses a lot of energy – when I was not able to join family or friends going to a restaurant or to the movies. After consulting a psychotherapist, I learned to accept the situation. Now, when I really want to go somewhere, I try not to do too much in the days before, to conserve energy. But honestly, deep inside my brain is an ambitious voice telling me never to accept SpA and fatigue. The dream that there will come a time when we
can treat fatigue in everyone with SpA keeps me going. I cannot do it by myself; we need each other. That’s why I would like to collaborate much more with people with SpA, because there is so much shared knowledge among patients.

Are there different kinds of fatigue? Do they originate in different parts of the brain?

Yes, there are. This is what I learned from both patients and animal studies. Fortunately, the eminent professor in rheumatology, Dr. Joel Taurog from the University of Texas Southwestern Medical Center, Dallas, was so kind as to provide us with an animal model with the human HLA-B27 gene. Surprisingly, there are at least three different forms of fatigue that can exist in SpA: 1) Motivational fatigue (I do not want to do anything); 2) Physical fatigue (I have difficulties performing physical tasks); and finally, 3) Cognitive fatigue (I have difficulties concentrating). Indeed, evidence is accumulating that different brain areas are involved in these different types of fatigue.

Let’s discuss treatments – medications and other options that may be helpful in battling fatigue. To start, does combating inflammation with medication always alleviate fatigue?

Fortunately, both NSAIDs and biologics can effectively reduce inflammation, but surprisingly these drugs have a much greater effect on pain than on fatigue. The hypothesis that I would like to investigate is that long-standing inflammation has changed the function and probably even the shape of brain cells. This would imply that once inflammation is lowered, brain function and the shape of brain cells do not automatically return to their original healthy state. At this moment, there is no proven effective therapy. This is one of the reasons why we desperately need to do more research!

Is there anything you personally find helpful in reducing fatigue? What does the research support?

It is too early to present solutions. At this moment, I am writing a grant to obtain funding to research food supplements that may be used to restore the neurotransmitter balance, the shape of brain cells, and brain functioning after inflammation. There is some evidence from other areas of brain research that walking every day for at least 30-60 minutes improves cognition, and may also reduce cognitive fatigue. Although this is not always easy with arthritis, remember that you can start small, because every step counts.

What is the future of fatigue research, and what do you hope to see on the horizon?

I am aiming for a cure. It is likely that a multidisciplinary approach is needed with biologics/NSAIDs as early as possible during disease development; specific amino acids and specific vitamins to restore neurotransmitter balance; psychotherapy to reduce stress and frustration; and daily exercise.

As someone living with spondyloarthritis and who understands the severe fatigue often associated with it, what do you wish others – your peers, friends, medical professionals, the general public – understood about the fatigue that you and so many others battle?

People do not choose to have a hyperactive immune system; they do not choose to have SpA or fatigue. It is fate. Fatigue is not a character flaw! It is a serious symptom of the disease, brought on by systemic inflammation throughout the body (including joints, gut, skin, and organs). It is this inflammation that prompts the brain to produce fatigue. People with SpA are not crazy or lazy, and they can perform much better when they receive support. Do not judge somebody with SpA or hold them to the same schedule that healthy people follow. In the mornings especially, motivational and physical fatigue can be responsible for a slow start. Yet research has shown that people with a chronic disease are often highly motivated to work and successfully carry on their careers. They just need support, understanding, and some flexibility in work hours.

Dr. S. M. (Mechiel) Korte is Associate Professor of Neuroimmunopharmacology, at Utrecht University, in The Netherlands. He is also a Guest Professor at the Institute of Cognitive Neuroscience at Ruhr-University Bochum, in Germany.

Pathophysiologica Mechanisms,” published in the peer reviewed journal, Rheumatology. This work was supported by the Dutch Arthritis Society. He also has a website dedicated to educating the public about fatigue, at www.whyfatigue.com
MORE research! imply that once inflammation is lowered, brain function and the effect on pain than on fatigue. The hypothesis that I would like to explain to healthy people how this fatigue feels. Unfortunately, I am aiming for a cure. It is likely that a multidisciplinary team of physiatrists, rheumatologists, and psychologists is needed to develop a treatment protocol that is effective and safe. There is some evidence that behavioral actions have higher energy costs than they typically sickness symptoms, such as fever or fatigue, in everyone, including people with SpA. In a way, fatigue has many similarities, but it is also unique to each individual. What is most important to me is that people with SpA feel heard and understood.

Are there different kinds of fatigue? Do they originate in the body or are they a result of our psychological state? Are there different brain areas involved in the experience of fatigue? Do we have any tools to treat it? What can I do to prevent fatigue in people with SpA? These are all questions that I hope to answer in my research.

Medical Center, Dallas, was so kind as to provide us with an agenda that may be helpful in battling fatigue. To start, does exercising for at least 30-60 minutes improve cognition, and may also treat fatigue in everyone with SpA keeps me going. I cannot avoid thinking about the audience raised their hands. Recently, the Dutch Arthritis Foundation tested a very large group of the population and the findings could be used to restore the neurotransmitter balance, the shape of brain cells, and brain functioning after inflammation. There is some evidence that behavioral actions have higher energy costs than they typically sickness symptoms, such as fever or fatigue, in everyone, including people with SpA. In a way, fatigue has many similarities, but it is also unique to each individual. What is most important to me is that people with SpA feel heard and understood.

What are the processes, chemical changes, and functions of people with SpA who suffer from fatigue? Remarkably, people with SpA who suffer from fatigue are highly motivated to work and successfully carry on their careers. This is understandable, because it plays a crucial role in reward-cost valuation. As you recover from an infection. But in inflammation in SpA is often chronic process, so consequently, we often suffer from chronic fatigue.

People with SpA are not crazy or lazy, they are so many ways your voice can help SAA continue to provide the services the spondylitis community relies on. You could sign up on Facebook to dedicate your birthday fundraiser to support SAA; grow a beard and ask for donations; or have your friends sponsor you to get your daily steps in. The possibilities are endless!

And remember, the most important component of your fundraisers is...your story. How did you become a SpA warrior? How has spondyloarthritis changed you or challenged you? Who are your heroes? Is your activity in memory or in honor of someone? What part of SAA’s core values of advocacy, support, research or education drives you to create a fundraiser? What’s your SpA superpower? How has SAA touched your life? Your story can inspire and highlight the reasons why it’s important to support SAA. We don’t receive any government funding. We rely on individual donations and family foundations to ensure our resources are available for the next generation.

SAA is here to be your platform. So, if you have something to share, we want to hear from you. Maybe your tale will become someone else’s second story as they pass it on to their friends. Your story has more impact than you know!

Contact Manny Caro at manny.caro@spondylitis.org or at 818-465-4290 to join our volunteer fundraiser program.
Fatigue and Brain Fog – A Mind-Body Approach

By Nancy O’Brien, C-IAYT, Certified Yoga Therapist

You wake up and begin moving your toes, knees, and hips, gauging the pain and stiffness in each joint. You’re tired. Tired in a way that sleep doesn’t fix, that rest won’t relieve. You dread sitting up and getting dressed. Even more, you dread the morning news – these days already feel strange and unfamiliar, and each new set of headlines sparks fresh anxiety and fear.

Fighting the inflammation of spondyloarthritis (SpA) leaves your body fatigued even on a normal day. But what is normal anymore?

The COVID-19 pandemic has tossed “normal” out the window, replacing our routines with disruption, isolation, and panic. Social distancing takes a toll on everyone, but especially those who live with a constant, quiet loneliness regularly. Brain fog is all too common as our minds process overwhelming loads of weariness and worry.

Fatigue and brain fog.

They are two of the challenges that, after pain, are most commonly cited by people living with SpA, and for many, they are in overdrive as we struggle to cope with the effects of navigating this new world.

What can be done to relieve these symptoms, to bring peace during these trying times? What can we do to support ourselves and our wellbeing?

Think of your energy as gas in a car. There’s only so much.

With SpA and other related conditions, here are some of the demands on that energy:

1. Processing medications
2. Dealing with significant physical challenges and inflammation
3. Constantly supporting the changing needs of the immune system
4. Dealing with pain
5. Absorbing the effects of too little sleep
6. Coping with mental stress (keeping up with doctors’ appointments, insurance issues, care-taking for yourself and others, finances, even depression)

And there are the basic functions – heartbeat, respiration, digestion, the often-challenged functioning of all our organs, muscles, bones, and brains.

Add in the extra strain of worrying about our health during a pandemic, and it can be even harder to keep gas in the tank.

Sleep vs. Fatigue

There’s a difference between being tired and being fatigued. Sleep takes care of tiredness. You wake up refreshed. Fatigue, though, doesn’t go away with sleep. Fatigue in arthritis conditions can be caused by any combination of the factors listed above. Pain itself creates fatigue. Mental and emotional stress create fatigue, not to mention the cumulative effect of too little sleep.

With brain fog, the confusion and inability to focus can result from the disease we’re battling itself, medications taken to manage it, as well as the many outside stressors acting as constant drains on our energy.

Compassion

I invite you to think about and appreciate how hard your body and mind are working! And know that you have the power to make things a bit more easeful with some fairly pleasurable – even a bit indulgent – breathing and relaxation practices. These practices may not make fatigue and brain fog go away, but they can help reduce their negative effects. And we know that taking care of our mental and emotional wellness has positive benefits for our immune systems.

We start with compassion. We all certainly deserve it.

First, embrace the many real causes of fatigue and brain fog. Realize you are not lazy or forgetful.

We see our bodies and minds sometimes as adversaries, which can make compassion difficult. But pity the poor hip we call “bad.” That hip, that “bad” foot or back, may be among the most challenged warriors in your body, trying despite great difficulties, to keep doing your bidding.

Honor your body and mind for their constant best efforts.

Start with summoning up compassion for someone in your life for whom it’s easy to feel compassion. Take a few breaths into that compassion and breathe out an intention of ease and release for that person. Then, switch out that person for your own image. Direct your compassion toward yourself, toward your body and mind, for doing their best in difficult circumstances. Try that with a few breaths whenever you need it.

Mini Meditations – Choosing an Intention

MINI MEDITATIONS – CHOOSING AN INTENTION

A breath to transport you to

A breath to deepen awareness

A breath to transport you

We move up the body:

1. Micro-bend the knees a few times.

1. Imagine, from the waist down, that you are the mountain above ground.

1. Take a moment to be present in your mountain pose.

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We see our bodies and minds sometimes as adversaries, which can make compassion difficult. But pity the poor hip we call “bad.” That hip, that “bad” foot or back, may be among the most challenged warriors in your body, trying despite great difficulties, to keep doing your bidding.

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MINI MEDITATIONS – CHOOSING AN INTENTION

A breath to transport you
We are always breathing. Bringing our focus to that breath opens a menu of possible mini-meditations. We can choose calming breaths, energizing breaths, or transporting breaths, to name a few.

Here are two examples:

**A breath to deepen awareness**

Breathing in, allow yourself to follow that breath in through the nose or mouth, down into the lungs, expanding your rib cage, your torso.

Breathing out, deepen your awareness of your body and mind, right now, in this moment.

Allow that breath out to be like a breeze gently soothing away any unnecessary holding in your mind or body, creating space for that next breath. Take a few breaths of awareness with an intention of accepting yourself exactly as you are in this moment, with compassion, whether you are tired, foggy, agitated, worried, or depressed.

**A breath to transport you**

Breathing in, ask yourself: Can I call to mind a place where I can feel openness, even pleasure? Can I imagine the colors, the sounds, the scents, the air on my skin?

Breathing out: Can I feel those sensations flowing through my mind, my body, gently nudging some of my physical tension or pain? Some of my worry or agitation?

The choices of intentions are only limited by your imagination. Gentle breathing practices de-stress the body and the mind, and you can either try relaxing breathing practices widely available, or use your own imagination anytime, anywhere.

**OWN THE MOMENT – MOUNTAIN POSE**

Bringing focus to our bodies can help transform stress and fear into support and spaciousness. Mountain Pose can calm the nervous system, halting some of the wasteful drains on our physical energy and restoring a bit of calm to the mind and heart. It can be done seated or reclining. It can also be done standing, but to feel – and be – safe, you can use a wall and/or a chair for support.

This can be a welcome respite for our often-challenged soles – and souls.

**We begin at our base:**

1. Lift your toes, as long as that is not painful. If it is painful or aggravates any difficult condition, simply visualize lifting your toes or just bring a kind focus – even a healing color – to your toes.

2. Even though it can seem impossible, if it’s comfortable, begin to try to lower – or visualize lowering – each toe on one foot. Then move to the other foot. If movement is aggravating, simply bring a kind focus to each toe separately.

**We move up the body:**

1. Micro-bend the knees a few times.

2. Bring shoulders gently up to the ears, then gently circle the shoulders back, and repeat. This movement can help bring openness to the neck and the front of the chest.

3. Gently tilt the head side to side, then gently forward and back, as long as this does not cause any discomfort.

**Become grounded:**

1. Imagine, from the waist down, that you are the mountain below ground, surrounded by bedrock.

2. Relax your back. Feel the support of the bedrock around you. Surrender into it.

3. Feel heavy from the waist down.

**Soar:**

1. From the waist up, feel that you are effortlessly rising, like the mountain above ground.

2. Allow a mindful breath to bring spaciousness and length between every vertebrae, every disk.

3. Bring the top of your head, the top of the mountain, a bit higher, closer to the sky.

**Become the mountain – still, powerful, majestic:**

1. Take a moment to be present in your mountain pose.

2. Become still. Inhabit your mountain.

3. Feel the power, the majesty, of being fully present.

Continue as long as it is comfortable. It can be very meditative, calming an overactive brain and relaxing a fatigued body.

Understanding that brain fog and fatigue have specific causes allows you to see that blaming yourself for forgetting, or feeling the need for a week-long nap, drains even more of your precious energy.

Surrender. Acknowledge your fatigue, your brain fog, your worry. These mind-body practices of presence with your breath, your mind, and your body can transform self-blame to acceptance, and frustration to compassion.

Are we breathing?
SAA/Bruckel Early Career Investigator Award – Introducing Our Latest Awardees!

As part of SAA’s ongoing mission to expand horizons in spondyloarthritis research, we strive to encourage and support new, upcoming rheumatologists and researchers in advancing spondyloarthritis research.

The SAA/Bruckel Early Career Investigator Award, created in 2001, recognizes outstanding “contributions to the care and understanding of patients with spondyloarthritis.” The award winner receives a $20,000 grant from SAA to use in spondyloarthritis research. The annual award is usually given to just one investigator; however, on occasions when the competition is too tough, SAA awards multiple $20,000 awards. This was one such year.

We recognize the numerous contributions of, and introduce our readers to, Drs. Danve and Liu.

Abhijeet Danve, MD, FACP, RhMSUS, MBBS
SAA/Bruckel Early Career Investigator Awardee
Assistant Professor of Clinical Medicine
Director, Yale Spondyloarthritis Program
Co-chair, Rheumatology Quality and Safety Council
Yale School of Medicine

Dr. Abhijeet Danve is a rheumatologist and Assistant Professor of Clinical Medicine at Yale University, with particular interest in clinical and translational research focused on early diagnosis of axial spondyloarthritis (axSpA). He is founding director of the spondyloarthritis program at Yale. Dr. Danve has contributed original research articles, systematic reviews and review articles in the field of axSpA. His publications in respected journals cover various aspects of axSpA such as biomarkers, screening and referral, treat-to-target strategy, the role of complementary medicine and comorbidities. He is a member of the Spondyloarthritis Research and Treatment Network (SPARTAN), and has served on the Registry subcommittee of SPARTAN since 2017.

Prior to joining Yale, Dr. Danve completed his clinical rheumatology fellowship at Oregon Health and Sciences University, Portland, OR and his research fellowship at University of Nebraska Medical Center. Dr. Danve is a recipient of the Marshall J. Schiff, MD Memorial Fellow Research Award (in 2013) and the Distinguished Fellow Award (in 2015) given by the American College of Rheumatology. He lives in Rocky Hill, CT with his wife, Supriya, and their two boys. He loves to travel and has a keen interest in Indian classical music.

General Research Focus

Dr. Danve’s current research is focused on early diagnosis of axSpA by applying efficient and cost-effective screening and referral strategies. Dr. Danve has developed an online clinical screening tool for early identification of axSpA and is currently conducting a funded clinical research study to evaluate its effectiveness. He is also trying to find new biomarkers for the diagnosis of axSpA.

Dr. Danve has developed a comprehensive multidisciplinary spondyloarthritis program at Yale with the aim of providing excellent care to axSpA patients and conducting high quality clinical and translational research. He is also interested in collecting patient reported outcomes and disease activity measures electronically to integrate those into EMRs (electronic medical records) for improving the quality of care delivery for axSpA.

How will the SAA/Bruckel award help support your research?

This award will support me in continuing my research on early diagnosis of axSpA to improve our patients’ symptoms, quality of life, and prevent late complications. It will also help me in expanding the Yale Spondyloarthritis program to become a center of excellence in the Northeast U.S. as well as building a patient cohort for high quality patient-oriented research. I’m grateful to the SAA and its membership for their support.
Shao-Hsien Liu, Ph.D., M.P.H.
SAA/Bruckel Early Career Investigator Awardee
Assistant Professor of Epidemiology
Department of Quantitative Health Sciences
University of Massachusetts Medical School

Dr. Shao-Hsien Liu is an Assistant Professor in the Division of Epidemiology, at the University of Massachusetts Medical School (UMMS). He is an early stage musculoskeletal epidemiologist with years of clinical practice as a physical therapist. One of his primary research interests is the application of advanced epidemiological methods using non-experimental data to assess the effectiveness of treatments in real-world settings. Dr. Liu has extensive experience using nationally representative samples with complex, multistage designs and observational data with measurements of patient-reported outcomes and physical activity. Dr. Liu is a member of the Spondyloarthritis Research and Treatment Network (SPARTAN) and the American College of Rheumatology (ACR).

General Research Focus

Dr. Liu’s research focus includes the application of advanced epidemiological and statistical methods to generate knowledge to ultimately improve quality of care for patients with spondyloarthritis (SpA). Specifically, he is interested and excited to further the understanding of disease trajectories in patients with SpA by focusing on measurements of patient-reported outcomes and physical function.

He is currently working on several projects related to SpA. In addition to conducting a systematic review of the literature on physical activity and attitudes towards exercise among patients with SpA, he is leading an analysis using clinical cohort data from the UMass Memorial Hospital (led by Dr. Jonathan Kay) to understand differences in self-reported physical activity and attitudes towards physical activity between patients with predominately axial versus those with predominately peripheral SpA. More recently, he was a recipient of the SPARTAN Seed Grant Award, which will allow him to conduct exploratory sequential mixed method design to address the root causes that drive sex- and gender-differences in reporting health quality of life among patients axial SpA.

How will the SAA/Bruckel award help support your research?

The SAA/Bruckel Early Career Investigator Award will help support me in activities directly linked to the research projects mentioned above. This in turn supports my long-term goal to become an independent, health outcomes researcher specializing in SpA research. I thank SAA and all those who make this award possible through their support.

Editor’s Note: You can learn about our past awardees, as well as about SAA’s involvement in research, on our website at spondylitis.org/Research.
Boosting Your Mental Health and Wellness Amid COVID-19

An interview with psychologist, Liz Maines, PhD

Wash your hands. Maintain six feet of distance. We’ve heard so much about how to protect our physical health during the COVID-19 pandemic. But in this era of self-isolating and staying at home, it’s just as important to take care of our mental and emotional health. We listened to questions raised by the spondylitis community and spoke with psychologist, and spondylitis warrior, Liz Maines, PhD, for tips on how to boost our sense of balance and wellness during this challenging time. Read on for an enlightening Q&A with Dr. Maines.

Q: There are still so many unknowns about COVID-19, and a flood of scary news reports. How can I combat the anxiety I feel?

Avoid falling down the rabbit hole of health-related news. If you do seek out information, limit your sources to sites you know you can trust, e.g. the Centers for Disease Control (CDC) or your state health department. Limit the amount of time that you watch the news or go online. Don’t leave the TV running in the background of your day. Talk with friends or family about your anxiety.

Q: A certain level of worry about COVID-19 is normal. But how do I know if I’m panicking unnecessarily?

Anxiety is a normal feeling during this very abnormal time. Remind yourself that other people are feeling anxious about COVID-19 too, and that you are not alone. Focus on the things that you do have control over.

• Self-care: bathe, dress for the day, take your medication, eat regularly, get good sleep, and exercise. If you are not doing these activities of daily living, you may need to reach out to a mental health professional.

• Practice breathing and grounding techniques. (Editor’s Note: Please see page 10 of this issue for examples.)

• Try not to Google symptoms.

• Try the Countering Technique – use rational countering statements to combat exaggerated negative thoughts. For example, if you’re having thoughts like this: “Everyone will die from this virus.” Counter it with a rational response: “Actually, most people who get COVID-19 are likely to make a full recovery, and that’s assuming the people I love will catch it in the first place.”

• Allocate yourself a daily “worry” period. Don’t worry outside of that allocated period. You can tell yourself, “I will think about this for 10 minutes at 9 a.m. and 9 p.m.”

• Treat yourself – cook something nice, or take a hot bath.
Q: It's hard to feel a sense of wellness when I'm stressed out and afraid. What can I do to practice self-care during this uncertain time?

Chronic stress is harmful to us. Often with the medications used to treat spondyloarthritis, our immune systems are already compromised, and stress exacerbates that. Therefore, it's critical to get back to your routine as much as you can. Exercise, stretching, reaching out to friends, engaging in activities that make you feel good (hobbies, volunteering from home, etc.) can all cut down on stress. Engaging in your routine will help you focus on the things that matter to you, which increases your wellbeing. Try reframing your mindset from, “I am stuck inside” to, “I can finally focus on my home and myself.”

Q: Some of us have suffered from severe anxiety, depression, or obsessive-compulsive disorder in the past, and worked hard to overcome them – but today’s situation is causing me to regress and relapse into my old symptoms and habits. Is there anything I can do?

Yes. Think back to the tools that helped you get better in the past. Re-engage in those practices or skills, such as cognitive behavioral therapy, journaling, or talking to friends. If that doesn’t work, contact your mental health provider. If you no longer have one, call the Behavioral Health number on the back of your insurance card or your state crisis line for a referral. Mental health professionals are working hard to provide therapy services through telehealth during the COVID-19 crisis.

Q: I’m immunocompromised and trying to take safety precautions to protect against infection, but my healthy family members aren’t taking the risk seriously. How can I express my concerns in a kind and effective way?

This is very challenging. If they do not live with you, do not meet with them in person right now if you can help it. Use electronic means for connection or communication, such as the computer or phone. Share simple but valid information with them. If they live with you, you must sit down and have a serious conversation about how you feel and what your risk factors are. You may want to explain that their actions (if they are not being careful) are putting you at risk. You can share information that you have found from reputable sites (the CDC, SAA, etc.). If it seems as though they really don’t care, then get some support from a mental health counselor. Your family/partner might be emotionally unhealthy and/or uncaring. That’s not a good situation for your physical or mental health.

Q: Due to the unpredictable nature of spondyloarthritis, I already miss out on social engagements regularly when I don’t feel well. Now that social distancing is the norm and we’re advised to stay home more often, I feel even more isolated. What can I do?

Reach out! Use the telephone and call a friend. Use Zoom, Skype or other video conferencing platforms (many are free) and engage in an activity together. For example, some folks are organizing virtual dinner parties. Join an SAA support group; most support groups are meeting virtually online now. If you’re involved in any other groups like a knitting circle, sports, or your church, call some of the members of your group and see how they are coping. Take a class online, like relaxation or yoga. Many of the services we can no longer access in person are being offered online.

Q: I’m calling my doctor much more frequently these days, since I can’t tell the difference between the flu, a cold, or seasonal allergy symptoms, and COVID-19. But I don’t want to strain my relationship with my healthcare provider. What communication advice can you share?

Educate yourself about the risk factors and symptoms of COVID-19. Know what to look out for, and if you have any of the signs or symptoms, call your healthcare provider or local health department to see if you should be tested. Don’t visit your physician without calling first. They are likely very overwhelmed right now. If you have any questions, make a list and ask them in one phone call or email. Start by saying, “I don’t want to strain my relationship with you, but I’m anxious. What would you recommend that I do?”

Otherwise, join a virtual SAA support group so that you can speak with others about your anxiety. We’re all a little hypervigilant right now, but sharing your anxiety with others may help.

Q: Any other tips for maintaining wellness these days?

Step out of the house from time to time if it is safe. Go outside and walk in nature. Go for a drive and enjoy your surroundings. Explore a new area or neighborhood. Remain as active as you are able to be. Just remember – six feet of distance. Be safe, stay healthy, and stay kind. We are all in this together.

Dr. Maines is a licensed clinical psychologist from Santa Fe, New Mexico. She is currently employed by a large government agency, but prior to that she was in private practice and worked with individuals with chronic and terminal illnesses. Dr. Maines and her wife (also a psychologist) enjoy the arts, history, and the music scene in Santa Fe. Dr. Maines, like many women, was diagnosed with ankylosing spondylitis later in life. She was first diagnosed with chronic iritis in 1995 and has struggled with chronic back pain her entire life.
Avoiding the ER Rollercoaster
By Gail Wright

My name is Gail Wright. I was diagnosed with ankylosing spondylitis (AS) in January of 2014. Prior to my diagnosis, I was active at the gym, doing all kinds of crazy things – from burpee challenges to body weight workouts, and dance parties holding weights. I had taken up running in 2009. I had learned to love running the Forest Preserve trails in Chicago with my dog and even took myself on 13 mile (half-marathon) runs for fun.

In December of 2013, that all changed when I experienced my first bout of costochondritis that led to my diagnosis of AS. Since 2014, I've gone through five lumbar surgeries, bilateral carpal tunnel releases, a left rotator cuff repair and a couple of kidney stone surgeries. Throw in a few epidural steroid injections and selective nerve root blocks for good measure.

After being involved in our local SAA spondyloarthritis support group for about a year, I decided to step up and take a leadership role. Through my experiences as a support group leader and my frequent interactions with doctors and hospitals, I've become a pretty good advocate for myself. I've learned how to speak up for myself, and collaborate with my doctors.

In August of 2019 I experienced pain like I've never had before. I couldn't even get out of my recliner. I waved the white flag and agreed to go to the ER by ambulance. Seven firemen and two EMTs gave me pain meds and managed to pick me up and load me into the ambulance. They were kind, compassionate and understood my level of pain. Ambulances take you to your closest ER – in this case, not the hospital I was familiar with. Upon arrival to this ER, I asked for my spine surgeon, who practiced at a different hospital, to be called. That was met with resistance. First thing they did was pull up my records. You can imagine the list of medications that popped up. The ER doctor couldn't even pronounce ankylosing spondylitis, much less understand what kind of pain I must be in. They ordered a CT scan of my lumbar spine. When that came back with nothing significant, the judgement got even worse. My husband by this time had gotten hold of my spine surgeon and he said, “Get out of that hospital immediately and come here. ” They loaded me up with enough pain meds that I could get off the table and have my husband drive me to the hospital where my spine team works.

Upon arrival to the second ER, I was again met with judgement and eye rolls. An MRI revealed more of nothing too exciting. I was admitted so that they could control the pain and do an epidural steroid injection. During my hospital stay, the hospitalist, who basically runs the show, was rude, judgmental and didn't provide proper care. The hospital didn't carry the anti-inflammatory that I take. After missing three doses, he asked me if I'd prefer to take something else, and proceeded to list a bunch of alternatives. I politely said, “Please call my rheumatologist. I don't make medication decisions. ” That never happened. My husband was finally allowed to bring my medications from home so the pharmacy could identify what I wanted to take and approve it.

I could go on and on about the improper treatment and judgement that I received while at this hospital – but believe it or not, that is not the focus of this article. I wanted to share my experience, and what I learned, to hopefully prevent others from experiencing this scenario. Looking back, having documents and action plans with me at the ER would have been helpful.

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I shared about my experience online, and SAA heard my story and reached out. We have been working together to create new resources to help those who may
find themselves in my situation – having to go to an ER for pain they cannot control and can no longer bear. Here are some suggestions we hope are helpful.

1. Develop a care plan. On this care plan, your health care providers’ numbers can be listed so that ER doctors or hospitalists can easily call, collaborate, and coordinate your care together.

2. The SAA has developed an informational sheet about spondyloarthritis that you can bring to an ER to help emergency care providers gain a basic working knowledge of the condition, associated risks, the medications we take, and how they work.

3. The SAA has also developed a template that you can use with your doctors to document your treatment and typical levels of pain/functioning. After working on the document with your rheumatologist or primary care physician, you can present it to emergency care providers to give them an understanding of how you typically function, as it may differ from how you present upon arrival to the ER. (Editor’s Note: Both of these resources are now available on our website, at spondylitis.org/medical-emergencies.)

4. Work with a case manager, if one is available to you. If you have health insurance, then you likely have access to a case manager (also called a care manager). This is usually a licensed professional such as a clinical social worker, registered nurse, nurse practitioner, or counselor. These individuals can act as your healthcare coordinator.

So many of us avoid the ER. My husband is under strict orders not to take me to the ER unless I have an actual bone sticking through my skin, I’m bleeding copious amounts of blood, or I’m unconscious. He knew it was bad when I said, “Make the call.” After the treatment I received in the ER and the hospital, I’m back to sticking to the above criteria. Hopefully I’ve turned my anger into actionable steps that can help myself and others be prepared to advocate for ourselves, and get doctors to collaborate to provide us with the standard of care we deserve.

I recently had the opportunity to work on a training video for doctors who would be prescribing a new medication. They wanted to include a patient’s perspective. After telling my AS story, they asked if there was anything else I’d like to say. As I said above, I’ve learned how to effectively communicate in order to, ideally, receive outstanding care. When I was in the ER in that level of pain, all those skills went out the window. I finished my interview by saying, “When I’m at my worst, I need you to be at your best.”

What is a Case Manager?

Case managers work with you to help ensure that your healthcare needs are met. They will ask about your health, and healthcare needs - emotional, mental, and physical - in order to determine, together, your primary health concerns. After identifying the highest priorities, you will discuss next steps, such as treatment options, barriers to treatment, coping methods, and social support systems.

What is a Care Plan?

A care plan is an individualized document that highlights the major health concerns you want to improve. It can include medical, psychiatric, substance abuse, and any other issues you may be dealing with. Once you approve the content, and give consent, this document can be sent to your physician, specialists, and any other healthcare providers as needed. As the patient, you co-create the goals outlined in the care plan with your case manager, and control which providers receive this. Care plans are tools that can ease communication between different providers in different settings. You can call your case manager as often as you need to clarify, enhance and receive help.

~ Jane Rosenblum, LCSW (Licensed Clinical Social Worker) and CCM (Certified Case Manager)

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You’re Not Alone!
Find all of our support groups at Spondylitis.org/Groups
More ways to connect at Spondylitis.org/Community
Want to speak with someone at SAA?
Call us Toll Free* at (800) 777-8189
and speak with a real live human being Monday through Friday!
*Toll Free available in U.S. only. International members can call us at (818) 892-1616.

Connect with Others Living with Spondylitis!
There are SAA-Sponsored Spondylitis Educational Support Groups in over 30 states throughout the U.S.
Is There One Near You?
SAA’s 2020 Global Spondyloarthritis Summit, featuring interviews with 12 international medical experts, is available for you any time at Spondylitis.org!

Watch as experts discuss topics including:

- Pain Management
- Advances in Treatment Options
- Diet & Nutrition
- Exercise
- Progress in Research
- Medicinal Cannabis

And More!

Find all of these presentations and more, available to members free, at spondylitis.org/global-spondyloarthritis-summit

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